

End of Life Planning Glossary of Terms

Acute illness – an illness with an abrupt onset from which the patient is expected to recover quickly and completely.

Advance care planning – The process by which an individual makes decisions and arrangements relating to their future healthcare. Such planning is carried out in two ways – by appointing a substitute decision maker or by completing an advance care directive.

Advance directive - A general term that describes two kinds of legal documents, living wills and medical powers of attorney. These documents allow a person to give instructions about future medical care should he or she be unable to participate in medical decisions due to serious illness or incapacity. Each state regulates the use of advance directives differently.

Agent - A designated person legally empowered to make decisions related to the health care of an individual known as a declarant, in the event that the individual is unable to do so; also known as a proxy or surrogate.

Aggressive treatment – Medications or procedures intended to cure or slow the progress of an illness

Anticipatory Grief – The deep emotional distress that can occur when someone has a life-threatening illness and death is expected. Anticipatory grief can feel just as painful as felt at the time of the actual death of the person.

Apnea – The cessation of breathing for a short period of time, usually lasting less than 20 seconds but sometimes lasting for as long as a minute.

Artificial nutrition and hydration – Artificial nutrition and hydration supplements or replaces ordinary eating and drinking by giving a chemically balanced mix of nutrients and fluids through a tube placed directly into the stomach, the upper intestine or a vein.

Bereavement – The process of grieving and mourning- in particular, the loss of a loved one- characterized by sadness and a deep sense of loss.

Best Interest - In the context of refusal of medical treatment or end-of-life court opinions, a standard for making health care decisions based on what others believe to be "best" for a patient by weighing the benefits and the burdens of continuing, withholding or withdrawing treatment.

Brain death – The irreversible loss of all brain function. Most states legally define death to include brain death.

Capacity - In relation to end-of-life decision-making, a patient has medical decision making capacity if he or she has the ability to understand the medical problem and the risks and benefits of the available treatment options. The patient's ability to understand other unrelated concepts is not relevant. The

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term is frequently used interchangeably with competency but is not the same. Competency is a legal status imposed by the court.

Cardiopulmonary resuscitation - Cardiopulmonary resuscitation (CPR) is a group of treatments used when someone's heart and/or breathing stops. CPR is used in an attempt to restart the heart and breathing. It may consist only of mouth-to-mouth breathing or it can include pressing on the chest to mimic the heart's function and cause blood to circulate. Electric shock and drugs also are used frequently to stimulate the heart.

Caregiver – An individual (usually not a medical professional) who provides physical and emotional assistance to a family member or friend.

Chronic illness – An ongoing condition or illness that doesn't respond completely to treatment.

Chronic obstructive pulmonary disease (COPD) – An ongoing condition characterized by poor, long-term airflow in the lungs that results in shortness of breath and productive cough.

CNA – Certified nursing assistant.

Comfort Care – Comfort care is an essential part of medical care at the end of life. It is care that helps or soothes a person who is dying. The goals are to prevent or relieve suffering as much as possible and to improve quality of life while respecting the dying person's wishes. Both palliative care and hospice care provide comfort, but palliative care can begin at diagnosis, and at the same time as treatment. Hospice care begins after treatment of the disease is stopped and when it is clear that the person is not going to survive the illness.

Cure Rate: means total elimination or eradication of the disease (i.e., with advanced heart disease- years of survival may be at 1 year-90%, at 2 years-80% and 5 years 15% but cure rates at 1,2, or 5 years are all 10%.

Declarant: the individual who is expressing his or her preferences regarding health care treatment, including end-of-life care.

Dementia- A decline in mental functioning that's more significant than would be expected due to aging.

Dialysis- is the process of filtering the blood through a machine via two small tubes inserted into the body in order to remove waste products from the body in the way that the kidneys normally do. Dialysis can be done temporarily in order to allow the kidneys time to heal or it can be done on a longer term basis in order to prolong life.

Do Not Hospitalize orders (DNH) - are medical orders signed by a physician, nurse practitioner or physician assistant that instruct health care providers not to transfer a patient from a setting such as a nursing facility (or one's home) to the hospital unless needed for comfort.

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Do Not Intubate orders (DNI) - are medical orders signed by a physician, nurse practitioner or physician assistant that instruct health care providers not to attempt intubation or artificial ventilation in the event of respiratory distress.

Do-Not-Resuscitate (DNR) order - A DNR order is a physician's written order instructing healthcare providers not to attempt cardiopulmonary resuscitation (CPR) in case of cardiac or respiratory arrest. A person with a valid DNR order will not be given CPR under these circumstances. Although the DNR order is written at the request of a person or his or her family, it must be signed by a physician to be valid. A non-hospital DNR order is written for individuals who are at home and do not want to receive CPR.

Durable power of attorney for health care – A legal document that allows all individual to name a particular person – known as an agent, surrogate or proxy- to make health care decisions on his or her behalf if he or she is no longer be able to make such decision; also known as medical power of attorney.

Dysphagia – Difficulty in swallowing.

Dyspnea – Difficulty breathing, especially during exertion or when lying down.

Emergency Medical Services (EMS): A group of governmental and private agencies that provide emergency care, usually to persons outside of healthcare facilities; EMS personnel generally include paramedics, first responders and other ambulance crew.

Emphysema- Destruction of the alveoli (air sacs) in the lungs that promote the transfer of oxygen from the air into the bloodstream, resulting in shortness of the breath.

End-stage disease- A term referring to the last phase in the course of a disease. It has, in large part, replaced the word "terminal" due to the negative connotations of the word.

Executor: a legal term referring to a person named to carry out the directions of a last will and testament. In many cases, the executor and the health care proxy are different individuals.

Failure to thrive: In the elderly, a diagnosis based on weight loss, decreased appetite, poor nutrition, and inactivity.

Fatal Disease: A fatal disease is in its natural course, will be fatal (i.e. Cancer, Heart Attack, Pneumonia) but with treatment, often is not fatal.

Futility: means vain, fruitless, serving no useful purpose, a severe disappointment; a futile treatment that cannot save a life.

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Guardian: A court-appointed individual granted authority to make certain decision regarding the rights of a person with a clinically diagnosed condition that results in an inability to meet essential requirements for physical health, safety or self-care. In Massachusetts not every guardian has authority to make health care decisions. If a health proxy is in effect, a healthcare decision of the agent takes precedence over that of the guardian (absent an order of the court to the contrary). Further, guardians who do have authority make health care decisions may be subject to limitations on their authority to make decisions regarding life-sustaining treatments.

Guardian ad litem - Someone appointed by the court to represent the interests of a minor or incompetent person in a legal proceeding.

Healthcare agent - The person named in an advance directive or as permitted under state law to make healthcare decisions on behalf of a person who is no longer able to make medical decisions.

Health-care treatment directive - A personal statement of an individual's preferences regarding health care treatment, including end-of-life care that is consistent with the legal underpinnings of living will statutes, where they exist. However, health care treatment directives are broader in scope than living wills because they are not limited to terminal conditions; also known as medical directive.

Health care proxy (HCP) – Is a document in which a person appoints a health care agent to make future medical decisions in the event that the person becomes incapacitated. This may be an outcome of the advance care planning process and is expressly authorized in Massachusetts by statute (MGL 201D)

Hemorrhagic- Refers to bleeding caused by the rupture of blood vessel.

Holistic Care- The treatment of the whole person, not just the clinical symptoms of a disease, including emotional, social, spiritual, intellectual and physical care for both patient and their loved ones.

Hospice - Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice and palliative care involve a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the person's needs and wishes. Support is provided to the persons loved ones as well.

Home and Community Care: Offer a range of supportive services provided in your home and other settings. Home and Community Care staff and nurses work closely with Palliative Care Services, and are usually the ones who first register people for our program of care when appropriate. Other Home and Community Care services for eligible clients may include:

- nursing
- physiotherapy and occupational therapy
- nutrition
- social work
- case management
- home support
- end-of-life care
- adult day programs

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- community clinics
- assisted living
- access to residential care facilities short term residential care for caregiver relief

Impending death- When death is expected in two or three days.

Incapacity - A lack of physical or mental abilities that results in a person's inability to manage his or her own personal care, property or finances; a lack of ability to understand one's actions when making a will or other legal document.

Interdisciplinary team – The staff members who comprise the hospice patient’s care team – typically a medical director, nurse, social worker, certified nurse’s assistant or home health aide, chaplain, volunteers, and grief specialist.

Intubation- Refers to "endotracheal intubation" the insertion of a tube through the mouth or nose into the trachea (windpipe) to create and maintain an open airway to assist breathing.

Ischemic- Refers to a lack of blood flow caused by an obstruction, as in a vessel blocked by a blood clot.

Legal guardian – A person who has the legal authority and the corresponding duty to care for the personal and property interests of another person. In many cases, the legal guardian and the health care proxy are different individuals.

Life-limiting condition or disease- A condition or illness that is progressive, fatal, and which cannot be reversed by treatment.

Life-sustaining treatment - Treatments (medical procedures) that replace or support an essential bodily function (may also be called life support treatments). Life-sustaining treatments include cardiopulmonary resuscitation, mechanical ventilation, artificial nutrition and hydration, dialysis, and other treatments.

Life-sustaining treatment/life support – Procedures or devices that replace or support vital body functions. Examples include cardiopulmonary resuscitation (CPR), breathing tubes, nutrition or hydration provided through tubes or intravenous (IV) lines, and kidney dialysis.

Living will - A type of advance directive in which an individual documents his or her wishes about medical treatment should he or she be at the end of life and unable to communicate. It may also be called a “directive to physicians”, “healthcare declaration,” or “medical directive.”

Long Term Care - Care in a facility that provides 24 hour professional care and supervision for people who have complex health needs. Staff members administer medications and assist residents who require help with daily activities such as eating, bathing and dressing.

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Long Term Care Home - A facility that is licensed by the province of Saskatchewan, also known as a nursing home or residential care facility.

Mechanical ventilation - Mechanical ventilation is used to support or replace the function of the lungs. A machine called a ventilator (or respirator) forces air into the lungs. The ventilator is attached to a tube inserted in the nose or mouth and down into the windpipe (or trachea).

Medicaid – State programs that provide health insurance to people who meet the criteria of being medically indigent.

Medical directive- a personal statement of an individual's preferences regarding health care treatment, including end-of-life care, that is consistent with the legal underpinnings of living will statutes, where they exist. Medical directives are broader in scope than living wills because they are not limited to terminal conditions; also known as health-care treatment directive.

Medical (or Physician's) Orders for Life-Sustaining Treatment (MOLST/POLST) – Is a document intended for seriously ill patients that documents decisions for life-sustaining treatment based on the patient's current condition. A MOLST from becomes effective immediately upon signing and is not dependent upon a person's loss of capacity. It does not take the place of a health care proxy. Consideration of MOLST may be an outcome of the advance care planning process.

Medicare Hospice Benefit- A provision available to anyone who qualifies for Medicare to receive the hospice benefit if they're assessed to be appropriate for hospice services (diagnosed with a life-limiting illness and a life expectancy of six months or less). All medications equipment, and supplies related to the life-limiting diagnosis are covered, along with all visits and services from hospice staff.

Medical power of attorney - A document that allows an individual to appoint someone else to make decisions about his or her medical care if he or she is unable to communicate. This type of advance directive may also be called a healthcare proxy, durable power of attorney for healthcare or appointment of a healthcare agent. The person appointed may be called a healthcare agent, surrogate, attorney-in-fact or proxy.

Metastatic – Refers to cancer that spreads from its organ or tissue of origin to other parts of the body. The cancerous cells are the same as those in the tissue of origin, so, for example, breast cancer cells may spread to bones, but this different than cancer that originate in the bones.

Occupational therapy- Instruction by a trained therapist in managing the activities of daily living-feeding oneself, dressing, toileting, etc. following injury, surgery, or illness.

Oncologist - A doctor who specializes in the treatment of people diagnosed with cancer. A radiation oncologist specializes in treating cancer with radiation therapy; a medical oncologist specializes in treating cancer with medications.

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Opportunistic infections- Bacterial or viral infections that would not normally cause a problem in a healthy individual but can become serious or even life-threatening in patients with impaired immune systems.

Palliative care - A comprehensive approach to treating serious illness that focuses on the physical, psychological, spiritual, and existential needs of the patient. Its goal is to achieve the best quality of life available to the patient by relieving suffering, and controlling pain and symptoms.

Physical therapy- Provided by a trained therapist, physical therapy is intended to allow the patient to regain normal mobility follow surgery, disease or injury or to maximize diminished physical strength and mobility to maintain as much independence as possible.

Physiotherapist - A rehabilitation professional who assists individuals in maximizing mobility and restoring strength and body movement.

POLST: an acronym that stands for Physicians Orders for Life-Sustaining Treatment and refers to a state policy that helps translate advance directives into a set of medical orders to make sure that a person's preferences are honored no matter where they receive care.

Power of attorney – A legal document allowing one person to act in a legal matter on another's behalf regarding to financial or real estate transactions.

Principle of Beneficence: This principle says that you should not receive a treatment that has less potential benefit than any potential risk incurred during diagnosis or treatment... sometimes the principle is referred to as "the principle of non-maleficence" which literally means "the doing of no harm."

Prognosis- An estimate, given by a doctor, based on the experience of many patients with the same disease or disorder who are similar overall health and age, of how the disease will progress. A prognosis may or may not include life expectancy, depending on the severity of the disease and the likeliness of the cure.

Proxy: a designated individual legally empowered to make decisions related to the health care of an individual, or declarant, in the event that he or she is unable to do so; also known as agent and surrogate.

Pulmonary- Relating to the lungs and their function.

Recertification- The process by which a written certificate of life-limiting illness is provided by the hospice medical director for each benefit period of the patient is on hospice. Recertification is possible as long as the patient continues to qualify for service as determined by the hospice medical director.

Remission- Refers to the stage of a chronic disease, such as cancer, marked by a lessening of the intensity or progression of symptoms (such as the presence of tumors), or cessation of the disease

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process (tumors diminish in size or disappear). Partial remission refers to a decrease in symptoms; in complete remission, there's no evidence of disease.

Respiratory arrest: The cessation of breathing - an event in which an individual stops breathing. If breathing is not restored, an individual's heart eventually will stop beating, resulting in cardiac arrest.

Respite care- Relief provided to the primary caregiver by a hospice volunteer who sits with the patient so the primary caregiver can leave the house. Most hospices arrange for several hours of respite care a week.

Respite stay- An arrangement made by hospice on a case-by-case basis to provide care for the patient for up to five days to provide a rest period for the caregiver. Care may be provided at any of several types of residential.

Surrogate decision-making - Surrogate decision-making laws allow an individual or group of individuals (usually family members) to make decisions about medical treatments for a patient who has lost decision-making capacity and did not prepare an advance directive. A majority of states have passed statutes that permit surrogate decision making for patients without advance directives.

Survival Rate: refers to how long a person lives with or without a cure.

Terminal Illness: a fatal disease that has advanced beyond the point of reasonable hope for a cure and usually means less than 6 months to live.

Ventilator – A ventilator, also known as a respirator, is a machine that pushes air into the lungs through a tube placed in the trachea (breathing tube). Ventilators are used when a person cannot breathe on his or her own or cannot breathe effectively enough to provide adequate oxygen to the cells of the body or rid the body of carbon dioxide.

Withholding or withdrawing treatment - Forgoing life-sustaining measures or discontinuing them after they have been used for a certain period of time.